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# **The experiences affecting Sub-Saharan African patients' engagement in antiretroviral clinical trials: an exploratory participatory action research study.**

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# Aims

Share, implement and disseminate good practice through identification of:

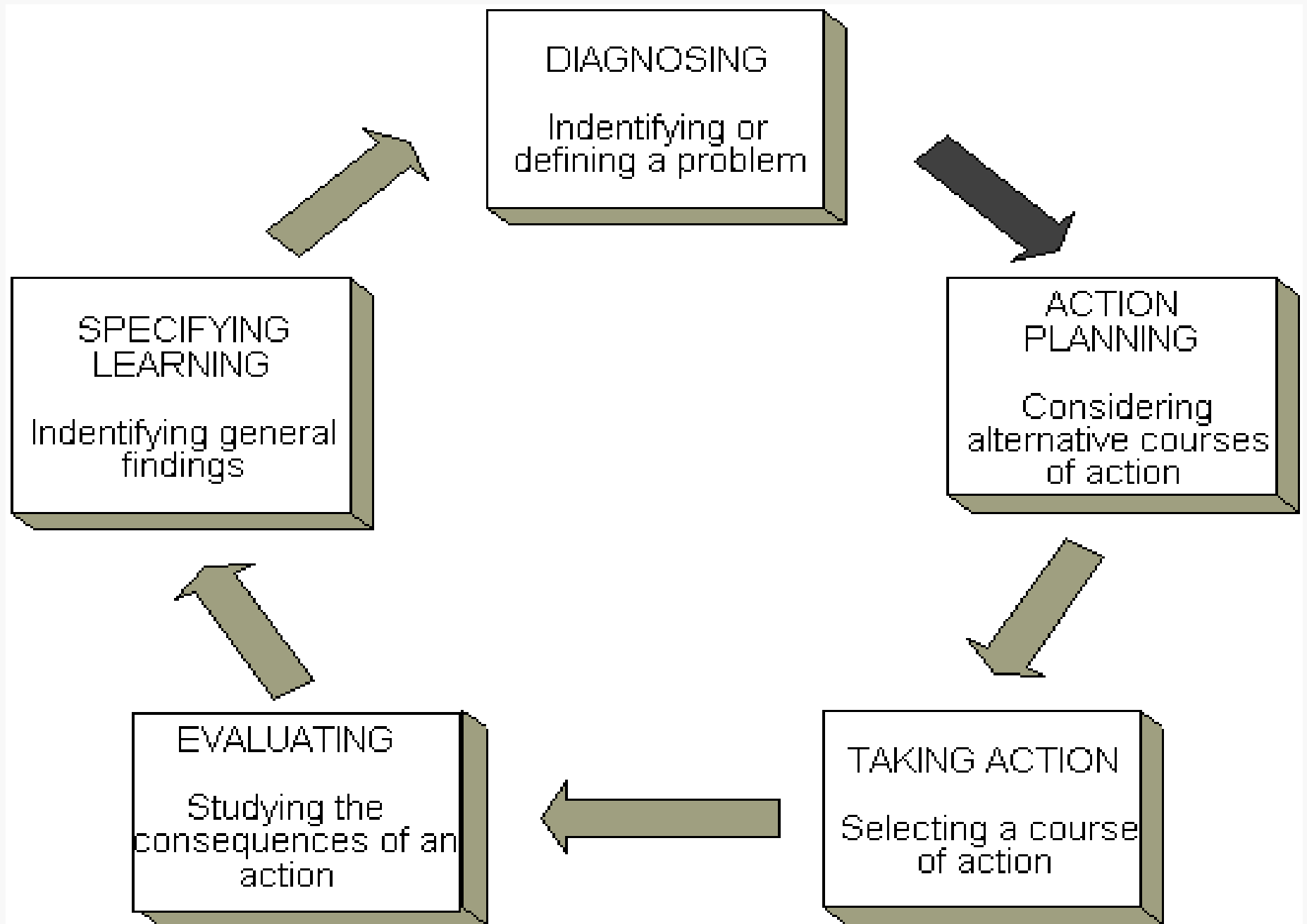
- clinicians/service users' perspectives;
- local knowledge that inhibits/enables subject engagement;
- factors that sustain adherence;
- factors that enhance local research capacity.

# Research questions

- what factors enable/constrain greater recruitment of sub-Saharan African patients into anti-HIV trials?;
- what factors facilitate/impede subject adherence whilst enrolled?;
- what service developments could accommodate above findings?;
- what inputs enhance social research capacity of research nurses?

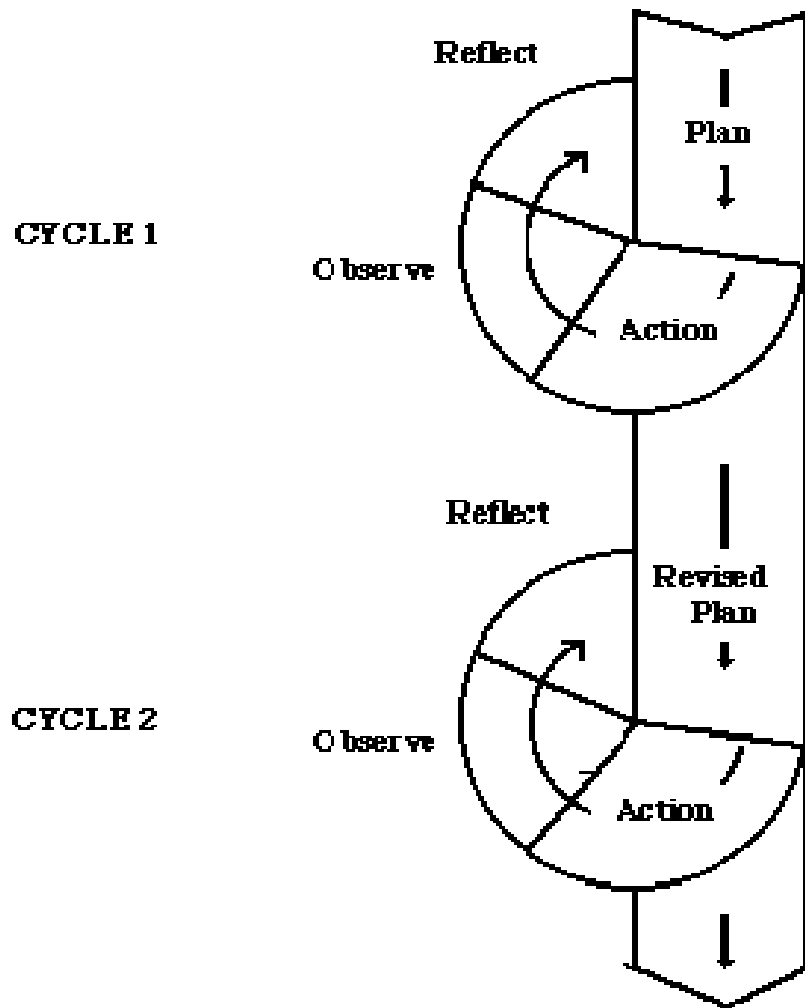
# Anticipated outcomes

- enhance enrolment strategies;
- increase African user consultation;
- developing clinical strategies in context of 'lay' health beliefs.



Gerald I. Susman, "Action Research: A Sociotechnical Systems Perspective," ed. G. Morgan (London: Sage Publications, 1983) 102

# Action Research Process (MacIsaac 1995)



Dan MacIsaac, "An Introduction to Action Research," 1995,  
<http://www.phy.nau.edu/~danmac/actionrsch.html> (22/03/1998)

# Participatory action research

(Stringer 1999)

→ Participatory action research aims to be:

→ democratic

- enables participation

→ equitable

- acknowledges equality of worth

→ liberating

- provides freedom from oppressive conditions

→ life enhancing

- enables expression of individuals' full potential



# Research advisory group (RAG)

- assists in achieving study aims/objectives
- invites participation of related communities
- forum to agree:
  - methodology
  - user involvement
  - data analysis
  - differing perspectives
  - social factors
  - ethical issues
  - funding
- engagement of related communities:
  - African professionals, users and patients
  - academic researchers
  - HIV clinicians

# Research advisory group (RAG)

→ Diverse communities of African professionals, patients/users, academic researchers and HIV clinicians with differing:

- roles/responsibilities
- tools & resources
- challenges
- interventions

<b>Related communities of ‘co-researchers’</b>	<b>Role/ Responsibility</b>	<b>Tools &amp; Resources</b>	<b>Challenges</b>	<b>Interventions</b>
<b>Academic researchers (co-opting Research Assistant &amp; African professionals from within the African communities)</b>	<ul style="list-style-type: none"> <li>•facilitate funding bids</li> <li>•establish RAG</li> <li>•co-ordinate data collection &amp; analysis</li> <li>•developing interview guide</li> </ul>	<ul style="list-style-type: none"> <li>•research expertise</li> <li>•opinion leadership</li> <li>•knowing community based issues e.g. recruitment sites, CBO’s</li> <li>•interview guide</li> <li>•African co-researchers</li> </ul>	<ul style="list-style-type: none"> <li>•knowledge of community issues</li> <li>•representation</li> <li>•knowledge of methodology</li> <li>•sense of alienation</li> <li>•project schedule</li> <li>•in-depth interviews</li> <li>•validity &amp; reliability</li> </ul>	<ul style="list-style-type: none"> <li>•recruit (co-) Research Assistant from African communities with local knowledge</li> <li>•recruit to RAG</li> <li>•seminars</li> <li>•lobby NASS, DoH re: RAS issues</li> </ul>

<b>Related communities of ‘co-researchers’</b>	<b>Role/Responsibility</b>	<b>Tools &amp; Resources</b>	<b>Challenges</b>	<b>Interventions</b>
<b>African users &amp; patients</b>	<ul style="list-style-type: none"> <li>•inform research process</li> <li>•active participation e.g. data, analysis, user involvement</li> <li>•provision of data, analysis of data</li> <li>•develop user involvement forum</li> </ul>	<ul style="list-style-type: none"> <li>•local knowledge</li> <li>•community networks</li> <li>•experience of problem/part of solution</li> </ul>	<ul style="list-style-type: none"> <li>•levels of knowledge</li> <li>•attitudes/belief systems</li> <li>•confidentiality</li> <li>•motivation levels</li> </ul>	<ul style="list-style-type: none"> <li>•invitation to RAG</li> <li>•referral to Services</li> </ul>

<b>Related communities of ‘co-researchers’</b>	<b>Role/ Responsibility</b>	<b>Tools &amp; Resources</b>	<b>Challenges</b>	<b>Interventions</b>
<b>HIV clinicians (physicians, nurse specialists, research nurses)</b>	<ul style="list-style-type: none"> <li>•provision of data</li> <li>•analysis of data</li> <li>•participate in developing user involvement forum</li> </ul>	<ul style="list-style-type: none"> <li>•patients’ trust</li> <li>•clinic setting</li> <li>•opportunities</li> </ul>	<ul style="list-style-type: none"> <li>•attitudes</li> <li>•power relations</li> <li>•overcoming perceived threats to professionals’/ boundaries</li> </ul>	<ul style="list-style-type: none"> <li>•transparency of information</li> <li>•invitation to RAG</li> <li>•increase visits to the clinic</li> <li>•more informal contacts</li> </ul>

# Contact details

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